



big sky BEHAVIORIST

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Etching by Charles Bragg

YOU ASKED FOR IT

Community-based services for the developmentally disabled citizens of Montana have grown rapidly in recent years. This issue of the Big Sky Behaviorist takes a close look at some aspects of that growth. The material presented here was gathered primarily from two sources. Staff of the Developmental Disabilities Division provided answers to thirteen frequently-asked questions about community services. In addition, interviews with four persons supplied facts and opinions representing various consumer and provider perspectives. We hope that this summary will be a useful reference for all those concerned with the developmental disabilities service system.

Q WHAT IS A DEVELOPMENTAL DISABILITY?

A According to state law [section 71-2402(2), R.C.M. 1947 (772)], a developmental disability is any disability attributable to mental retardation, cerebral palsy, epilepsy, autism or other neurological handicapping conditions closely re-

lated to mental retardation and requiring similar treatment. It must have originated before the person attained age 18 and it must be a continuing disability constituting a substantial handicap.

Q BRIEFLY, WHAT IS THE HISTORY OF SERVICES FOR DEVELOPMENTALLY DISABLED INDIVIDUALS IN MONTANA?

A Over the past one hundred years, Montana has established a dual system of service to its developmentally disabled residents. One system functions within communities and the other in institutions. In the past, physicians generally recommended institutional placement of

developmentally disabled persons. Originally intended as schools, institutions became warehouses; little teaching occurred and living was at sub-human levels. Periodic attempts at teaching by isolated staff led to few improvements due to overcrowded facilities and insufficient re-

sources. Institutions were generally viewed as the appropriate placement; therefore, families found few services available in their communities outside the institution. Despite the lack of community services, some families refused institutional placement. These families were one factor in the movement which established the foundation for today's community-based services.

The late sixties saw a shift in the public attitude toward mental retardation as a result of increased knowledge and awareness. This was partly due to the Kennedy and Humphrey families' decisions to openly and personally address the plight of the mentally retarded and their families. Another important factor was passage of federal legislation -- for example, the Community Mental Health Centers Act of 1963. Services were scrutinized, funds became available, and alternative services were developed.

Innovative and aggressive action in the early seventies brought improvement and individualization of services to developmentally disabled persons in Montana. An integral part of this development was the gradual reentry of these individuals into communities. A network of community-based services was developed throughout the state, resulting in a broader base of support. More appropriate services became available in both institutions and com-

munities. Many individuals who were inappropriately institutionalized returned to the community. The likelihood of these tragic errors recurring was decreased by careful diagnostic and evaluation procedures.

Much of the impetus behind the movement toward deinstitutionalization came from institutional staff who actively sought community placements, provided transitional support to individuals returned to the communities, and discouraged new institutional placements. Quality training programs were developed for those remaining in the institution. The seeds of advocacy were planted by Boulder staff when they made demands on behalf of the individuals they served, informing the public of conditions at the institution and of possible alternatives.

During the 1975 legislative session, private citizens, institutional staff, community program staff, and state elected officials developed a plan for community-based services with an interim program for the institutions. Changes were made in Montana law. Substantial funds for both the communities and the institutions were appropriated for implementation of these new programs.

Variety and availability of services continue to develop with increasing emphasis on effective management and improving the quality of services.

Q WHAT IS DEINSTITUTIONALIZATION?

A Deinstitutionalization refers to the process of returning institutionalized individuals to the community. Although the process has been going on for some time, the term was coined only recently to describe the implications of court decisions affecting institutionalized developmentally disabled persons. Beginning as a humanitarian movement,

deinstitutionalization evolved into a legal issue as the result of significant court decisions. One landmark decision was the Wyatt vs. Stickney case. It called for treatment in the least restrictive alternative -- specifically defined as living environments: movement to less structured living, to smaller facilities and smaller living units,

and to individual residences within communities.

According to the Department of Health, Education, and Welfare, the concept of deinstitutionalization has three components.

1. Returning institutionalized residents to local communities where they can lead useful, productive lives, while reducing the populations of institutions.
2. Preventing further inappropriate admissions to insti-

tutions by serving developmentally disabled persons in the community.

3. Improving the quality of care given to those persons who are currently residing in institutions.

Within Montana, deinstitutionalization has meant the development of a network of educational, residential, and support services in communities across the state for persons who need such services.

Q DESCRIBE THE TYPES OF COMMUNITY SERVICES THAT EXIST FOR BOTH CHILDREN AND ADULTS.

A All services to developmentally disabled citizens which are mandated by state law are provided by the Developmental Disabilities Division, with the exception of long-term residential service (i.e., domiciliary care). It is provided by the Department of Institutions.

Adult community services include (1) residential services such as semi-independent living and community group homes and (2) auxiliary services such as transportation, vocational training, evaluation and diagnosis, and respite care. Residential services provide skill training and living arrangements with varying degrees of supervision. Transportation services are supplied so that adults may utilize day training programs and other community services. The range of available vocational services is broad. Generally, vocational services involve training in pre-vocational and vocational skills with the goal of competitive and gainful employment.

For the family with a developmentally disabled child, services available include respite care, community group homes, family training and resources, and evaluation and diagnosis. Respite care provides individuals with short-term instruction and care by trained staff so their natural or foster parents can spend some time away from home. Community group homes for children, like those for adults, provide supervised living situations and training in developmental skills. Family training and resource services supply family members with instruction in training procedures. Knowledge of these procedures enables family members to carry out prescribed developmental activities and the training of their child. Evaluation and diagnostic service, available to developmentally disabled persons of all ages, refers to assessment of an individual's level of development.

PERSPECTIVE:

Gary Pagnotta



Gary Pagnotta is Program Director of Bozeman's Reach, Incorporated. Reach, Inc. is a non-profit organization which provides a variety of services to developmentally disabled individuals. It operates residential facilities (i.e., group homes, semi-independent living arrangements) and facilities specifically for training (e.g., sheltered workshop training, day programs).

Q. *Do you agree that public awareness is necessary to the future of services for Montana's developmentally disabled people?*

A. Definitely. Public awareness is essential to the future of community-based services. Originally, it was fully the intention of the system to try to bring in as much local community support [as possible].

Basically, we're returning individuals from institutions and putting them into community services [in order] to truly integrate them into the community. To really be doing that,

there needs to be acceptance of handicapped individuals in the community.

Q. *What concerns do you have about the current extent of the public's awareness of community services?*

A. Due to the negative publicity regarding community-based services [resulting from] the audit, there is reason for much concern about the future of community-based services. There has not been an effective rebuttal. There really needs to be [a] campaign -- some effort made by all components of the system: state staff, regional staff, and especially community-based programs. [That would mean] talking to individuals, reaching key individuals such as legislators -- to project a positive image. Mistakes have been made, [but] basically community services have succeeded. [There are] many positive things to be said to the public as well as to individuals that have control over the future of our programs.

Q. *Who do you see as primarily responsible for increasing the public's level of awareness?*

A. Ultimately, the responsibility lies [with] the state office of developmental disabilities [and] with local programs. The major effort has to [come

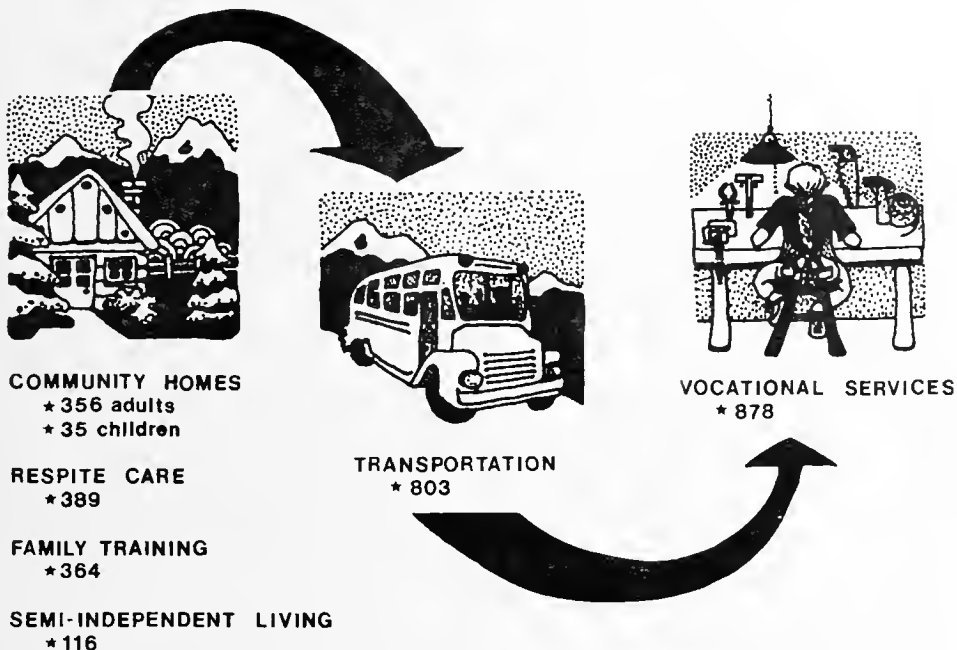
from] the local programs. In my area in Bozeman, it never ceases to amaze me how many people still come up to me [having] absolutely

no conception of who we are and what we do. I've recognized -- being here three years -- that there is a track record and most [of the] feedback I receive [regarding our program] is positive. [Informing the public] needs to be an ongoing process -- it's got to be done. ■

THERE NEEDS TO BE ACCEPTANCE OF
HANDICAPPED INDIVIDUALS IN THE COMMUNITY

Q HOW MANY CLIENTS ARE BEING SERVED IN EACH TYPE OF COMMUNITY SERVICE PROGRAM?

A The figures below reflect the number of clients being served in Montana community programs as of June 1978.



Q WHY ARE COMMUNITY SERVICES OUTSIDE THE INSTITUTION CONSIDERED BETTER?

A Community-based services are considered "better" because institutions often are unable to provide opportunities for individual development. The large number of people within an institution typically results in varying degrees of depersonalization, loss of individual autonomy, and regimentation in both living environment and daily activities.

A much smaller physical environment is an advantage of community-based services. Smaller scale programs are more conducive to individualized attention in all aspects of a developmentally disabled person's life. In addition, a wider variety of activities -- both educational and recreational -- promote individual growth and the opportunity for choice and independence.

PERSPECTIVE:

John Cooper



John Cooper, a prominent Helena businessman, has been Chairman of the Board of Directors of Helena Rehabilitation Industries for the past two years. Prior to that, he was associated with the Board for four years.

Q. *Do you agree that public awareness is necessary to the future of services for Montana's developmentally disabled people?*

A. Oh, absolutely! Public awareness is an absolute necessity. One of the problems is that people are apathetic. People tend to be selfish and consider their own needs first. Disabilities and rehabilitation [are] not directly related [to] most of the public's day-to-day needs. It's mandatory that somehow, some way, we get the point across to the public that there is a hope for these people, there's a salvation for them -- they can be trained and made an integral part of the community.

Q. *What concerns do you have about the current extent of the public's awareness of community services?*

A. As I said before, public apathy [concerns me]. The way our government is nowadays -- it's big and there are so many things we have to adhere to and so many things we have to do -- it's a tough job just making your own way with your own problems without recognizing somebody else's.

There seems to be a spirit of people waking up -- they are looking at things now. They're screaming about tax reform and too much government. Eventually it's going to filter down into individual areas where the rehabilitation of the people we deal with [becomes] extremely important.

Q. *Who do you see as primarily responsible for increasing the public's level of awareness?*

A. The more SRS can do the better. Also, it's a responsibility of all of us that have anything to do with rehabilitation programs to keep ourselves out in the forefront.

We [at HRI] have an active PR program. We're constantly pushing newspapers to get feature stories and articles done on the people we work with. . . . I'm constantly amazed at the number of people who don't know what Helena Industries is. We've changed the name from Helena Industries to Helena Rehabilitation Industries because [there's] a business in town called Alpha Industries that makes whiskey. A lot of people confused us with [them].

WE'VE GOT A BETTER AX TO GRIND BECAUSE
OUR PRODUCT IS REHABILITATION OF PEOPLE

Q. *What recommendations or ideas do you have for increasing the level of public awareness?*

A. In the past six years I've watched SRS grow up, and they have had a lot of growing pains. I think they have done really a magnificent job. They have been hampered a lot by excessive government regulations [and] a lack of funds. Then you look at the other side of the coin -- sometimes the funds aren't managed properly. This causes a backlash. The legislature turns back on SRS and says that they're not doing their job right [but] any business of any size is always going to have certain problems.

To really get down to the nut and bolt answers of getting this awareness to the public, I can say right now we need, from all

sides, a more positive attitude. The media has harmed us in a lot of respects. They go on witch hunts. They look for the things that cause sensationalism. We need more human interest stories of accomplishment in what we're doing -- a good public relations program that really brings this out. If that can happen, the legislature is going to be more receptive, too.

We can increase public awareness through community action programs, but this is hard to do because . . . you're competing with other groups. We've got a better ax to grind because our product is rehabilitation of people who were unfortunate at birth or through accident and had problems loaded on them. They're human beings and often tend to get shoved in a corner and forgotten. If we can show [the public] that what we've got is more important, I think we'll win the battle. Somehow we're going to do it. ■

Q. WHAT IS THE ROLE OF THE DEVELOPMENTAL DISABILITIES DIVISION IN THE PROVISION OF SERVICES?

A. State law [section 71-2404(4) R.C.M. 1947 (353)], passed by the 44th legislature, provides for community-based services to developmentally disabled persons. The Developmental Disabilities Division was given primary responsibility for insuring the success of those services. The Developmental Disabilities Division is responsible for developing community residential, training and auxiliary support services. Regional Councils made up of consumers and professionals assist in this effort. These councils have provided

the local impetus needed to generate support for the developing community programs.

The Developmental Disabilities Division provides funding through contractual arrangements with local provider agencies, typically non-profit corporations. These make up the service network which allows developmentally disabled individuals to move into less restrictive community living situations.

Q. ARE APPROPRIATE SERVICES STILL LACKING?

A. Yes. Though Montana has developed an impressive number of services in a relatively short period of time, there are needs which remain to be met. Examples include prevention of developmental disabili-

ties, alternative living arrangements, accessible transportation, public education and awareness, additional training and support for families of the disabled.

PERSPECTIVE:

Keith Colbo



Keith Colbo is Director of the Department of Social and Rehabilitation Services in Helena.

Q. *Do you agree that public awareness is necessary to the future of services for Montana's developmentally disabled people?*

A. I would go further than just saying "necessary." I think it's vital to the success and continuation of the program. With awareness will come support -- including [that of] legislators, who are vital to the program in terms of plotting the future.

Q. *What concerns do you have about the current extent of the public's awareness of community services?*

A. My main concern is that [the public] gets proper information [about] the programs -- what [the programs] are intended to accomplish, what their presence in the community means, and just what the

program is. There are a lot of misconceptions and fears about developmentally disabled populations in the communities. There are a lot of misunderstandings; familiarization with the programs should alleviate many of those problems.

Q. *Who do you see as primarily responsible for increasing the public's level of awareness?*

A. The program itself in the local community. It's far better coming from that level than coming from Helena and the SRS officialdom. [The public] is far more likely to respond to the legitimate needs and requirements [of the program] if coming from their own people and community.

Q. *What would you say to the neighbor who says, "We've been pumping a lot of our tax dollars into developmental disabilities for years. Now there are other priorities."?*

A. The job is not done. We can inventory almost every community and region and find needs not being met. [We need to] realize that the emotion is shifting from developmental disabilities -- that caring and compassion has been felt and it's been reduced to dollars. Montana [stands] well in comparison with other states [in] program accomplishments -- primarily in the community, [but] the job is not done.

CARING AND COMPASSION HAS BEEN FELT
AND IT'S BEEN REDUCED TO DOLLARS

Q. *What recommendations or ideas do you have for increasing the level of public awareness?*

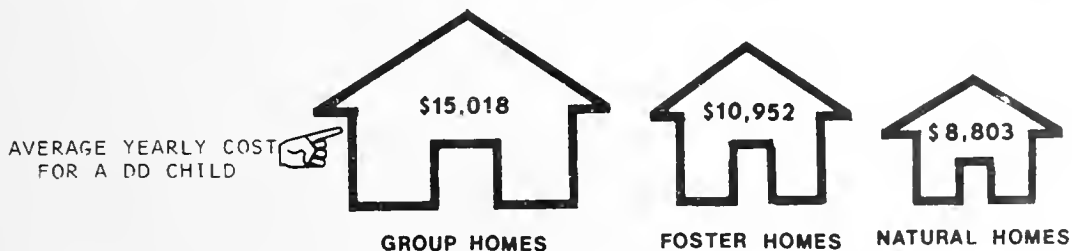
A. I think we come back to the local board and involvement of the local people, beginning with the neighbors -- whether it be with the sheltered workshop, the group home, the foster home, whatever. . . . We've seen [increased

awareness] in those communities that have had success. There will be bad incidents, as there are in the general population. The better [the] understanding about the program and the clients, the more apt we are to have a realistic reaction should an incident occur.

[I]n the trips I have taken out in the field to see some of these programs and meet with local board members and members of the community, I find more support -- a willingness to take on whatever the needs of the program are in the community. It's very refreshing to see. ■

Q WHAT DETERMINES THE AVERAGE COST OF A FULL RANGE OF SERVICES FOR A DEVELOPMENTALLY DISABLED ADULT OR CHILD?

A The range of services for a client is largely a function of the residential option chosen. For each option, the average total cost of services available is reflected in tables 1 and 2 below -- figures as of June 1978.



SERVICES FUNDED BY DD DIVISION

Adaptive Equipment	■	■	■
Evaluation and Diagnosis	■	■	■
Administration	■	■	■
Family Training		■	■
Respite Care		■	■
Early Intervention		■	■
Residential Payment	■		
Direct Training	■		

SERVICES FUNDED FROM OTHER SOURCES

Medical Support	■	■	■
Special Education	■	■	■
Case Management		■	■
Foster Care Payment		■	
Room, Board, Clothing from Natural Family			★

★ No average costs exist for room, board, and clothing for a DD child living in the natural family home.

■ TABLE 1. SERVICE OPTIONS AND AVERAGE YEARLY COST FOR DD CHILD ■

Cost of training a group home resident is greater than that of training a client in a semi-independent living arrangement. Consequently, the average cost for adults is higher if they reside in group homes.



GROUP HOMES
\$12,581

AVERAGE YEARLY
COST FOR A
DD ADULT



**SEMI-INDEPENDENT
LIVING**
\$10,884

SERVICES FUNDED BY DD DIVISION

Day Program
Transportation
Administration
Direct Training

SERVICES FUNDED FROM OTHER SOURCES

Supplemental Security Income
Medical Support
Case Management

■ TABLE 2. SERVICE OPTIONS AND AVERAGE YEARLY COST FOR DD ADULT ■

Q WHAT IS THE MECHANISM FOR PROVIDING COMMUNITY SERVICES?

A Community services are provided through purchase of service contracts. There are approximately 135 contracts for services and approximately 60 providers (some providers supply more than one service -- each under a separate contract). Contracts for specific services such as community group homes are negotiated typically with local non-profit corporations. These corporations hire staff to deliver direct training services. Services provided are

monitored for both programmatic and fiscal accountability by staff of the Developmental Disabilities Division.

Other community services are provided by different agencies within the Department of Social and Rehabilitation Services, including the Rehabilitation Services Division and Social Services Bureau. Local school districts, volunteer organizations and private corporations offer additional services.

Q WHAT PROCESS IS USED TO DETERMINE APPROPRIATE SERVICES FOR ADULT CLIENTS?

A

NEW CLIENT

COUNTY SOCIAL WORKER
Provides referral information

SCREENING COMMITTEE

Makes decisions on appropriate client services. Determines client's acceptance into evaluation and assessment service programs.

SERVICE PROGRAM

Develops Individual Program Plan (IPP) with objectives and evaluation. Periodically reports to the IHP team.

**INDIVIDUAL HABILITATION
PLAN (IHP) TEAM**

CLIENT, CASE MANAGER, AND REPRESENTATIVES
OF ALL DD SERVICE PROGRAMS AND PROVIDERS

Identifies and coordinates service and training needs by establishing goals, timelines, and responsible program persons.

Identifies service needs such as mental and medical health and vocational rehabilitation services. Initiated by the case manager.

Meets at least every six months for reevaluation with information from service program staff.

PERSPECTIVE:

Vonnie Koenig



Mrs. Koenig, parent of a developmentally disabled young man, is chairperson of Region V's Developmental Disabilities Advisory Council.

Q. *Do you agree that public awareness is necessary to the future of services for Montana's developmentally disabled people?*

A. Yes, absolutely! Not only necessary, but vitally important to the continuation of programs for the developmentally disabled. One of the dangers of a program like this is complacency -- taking for granted that because this year we have a good program, [meeting] the needs of most of the people, that this program will continue next year and the year after. I think we all realize that because of the competition for the tax dollar we're going to have to be very accountable.

IS THIS A PERSON WORTH KEEPING,
WORTH HAVING AROUND?

Q. *What concerns do you have about the current extent of the public's awareness of community services?*

A. Who do we identify as the public? The people we want to reach [with] our services and programs are the developmentally disabled themselves, their parents, families, and advocates. We need to help them [determine] which services are best. It's absolutely critical that there be a very close working relationship between parents and the medical profession -- the people that first see the developmentally disabled person. More should be done in this area.

Another group is legislators -- the folks who have a great deal to say about fiscal matters relating to the quality of life that our developmentally disabled will have. It is the responsibility of those of us who are parents and professional people to make [legislators] knowledgeable about the services and programs in their own community so that they can relate to the programs in terms of actual people, instead of statements and figures.

Then [there is] the general public -- all those neighbors, friends, businessmen -- anyone who might come in contact with the developmentally disabled in the community. Only as these folks understand something about the potential or the needs of the developmentally disabled will they be able to relate to them in a meaningful way. [They need to know] that this person is probably more alike than different [from them].

Q. *Who do you see as primarily responsible for increasing the public's level of awareness?*

A. That is a tall order for each and everyone. I see parents as being primarily responsible, although sometimes it is one of the most difficult things a parent can do. Anyone who considers himself a concerned citizen really has

that responsibility, whether as a lay or professional person.

Q. *What recommendations or ideas do you have for increasing the level of public awareness?*

A. A couple words come to mind: commitment and involvement. [For] those who really care what happens to the developmentally disabled, there has to be this commitment that you will do all the kinds of things you can to make life meaningful. This, of course, requires involvement. On a local level, associations for retarded citizens are an ideal place for parents and professional people to get together to increase their knowledge and understanding about the developmentally disabled person -- what they can do and maybe some things they can't. That's where it all starts.

Q. *What would you say to the neighbor who says, "We've been pumping a lot of our tax dollars into developmental disabilities for years. Now there are other priorities."?*

A. [This] goes back to [how] we feel about a person who may be of less ability intelligence-wise. Is this a person worth keeping, worth having around? Do you believe that this is a person whom God also created and had a purpose and plan for? A developmentally disabled person is just as important as anyone else in our society. We dare not say to ourselves, "We've done something for them, they should be satisfied now." We're going to keep going forward and not even think about going backward.■

Q HOW DOES CASE MANAGEMENT WORK FOR ADULTS?

A Case management arranges and provides for coordination of all services being delivered to each individual. It ensures delivery of service and reduces inconsistency, confusion and duplication. The case management procedures followed in Montana have not been consistent across regions, counties and workers. Some of the variation may be explained by:

1. the lack of any detailed procedural/performance guidelines,
2. the wide range of educational and philosophical backgrounds of individual case managers, and
3. the administrative difficulties which result when two separate divisions

are involved in a single task. (The Developmental Disabilities Division is basically responsible for the provisions of services while the Community Services is responsible for case management.)

Case management essentially includes the following responsibilities: initial eligibility determination, client needs assessment, appropriate service placement, follow-along, counseling, assistance with client financial problems, arrangements for IHP meetings, monitoring of services and goal attainment, and decision-making in crisis situations. Working properly, case management acts as an advocate for the developmentally disabled person involved in the multitude of available services and agencies.



ARE THERE PEOPLE IN MONTANA NEEDING SERVICE?



Yes, there are waiting lists for some of the services to developmentally disabled persons in Montana. These are primarily in the adult service areas such as day training programs, community group homes and transportation services. During the past two years, funding has remained essentially the same with only small inflationary increases. Despite this fact, more individuals are being served now than previously. There were 1,472 persons receiving service in July 1978 compared to the 1,289 being served in July 1977.

There is, however, a point at which service providers cannot increase the number of clients served without additional funding. Two factors limiting expansion are physical space and the availability of program staff to work with clients. When a program opening occurs, screening committees carefully consider the selection of new clients. Waiting lists have been developed to insure that all potential clients are considered by the committee. All regional developmental disabilities offices currently collect waiting list information in order to identify unaddressed service needs.

STAFF OF THE DEVELOPMENTAL DISABILITIES DIVISION CONTRIBUTING ANSWERS TO THE THIRTEEN QUESTIONS WERE:

Janice Frisch	Program Manager
Ken Gossett . . .	Chief of Client Community Services Bureau
Jim Meldrum	Chief of Resource and Planning Bureau
Erich Merdinger	Resource and Planning Bureau
Gary Meyers	Program Manager/Special Projects
Mike Muszkiewicz	Training Coordinator
Pat Sharp	Program Manager
Linda Worsdell	Client Service Specialist

For
Everything
there is
a Season...



bsb

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